



A rule for an ME Advocate

You are responsible to represent the person, not yourself.

You are standing in for the person, to get their needs totally met, to speak for them.

It is not your position to be overly nice to whoever you are talking to and so accommodating of their situation that you compromise the position of the person you are supposed to be representing.

There may be two sides to a story but you need to be clear which side you stand on; it is the person's.

It is your duty to be assertive on behalf of the person you represent, even if it doesn't come naturally to you. Anything else will lead to the potential negation or minimising of the person's reality.

Compromise concerning health or symptom experience is unacceptable.

You need to be polite but you don't need to be popular; you need to be assertive for the truth however uncomfortable that makes you feel.

You can't make everyone happy necessarily. The person you are trying to please is the person you are advocating for. Unfortunately with ME everything is compromised because the term "ME/CFS" compromises everything. Make sure you don't compromise too.

You have to come from a centre of truth and integrity, with a lived commitment to understand the person's reality. Too much care is focused upon clientising people rather than empowering and enabling them.

Your position is the assertion of the person's equality of person-hood, nothing else.

You have to be very clear about your boundaries and understand how they work so that you do not get caught up in someone else's "poor me/us" story or game.

You need to have negotiating skills, you need to know how to play to win. You need to have a solid grasp of the issues and facts, so that you are not outwitted by the other's "yes/buts", leading you away from truth to their relative view. Be aware of how relative views corrupt truth.

You have to stand firm for the truth of ME and the person's reality especially where others are angry, limited, misinterpreting or compromising the need. The physical reality of ME is not negotiable nor open to compromise. It is a serious neurological disease, with multi-system dysfunction that has a profound effect on the person's life.

Do not be fobbed off with something that is not suitable but makes the other feel self-justified - or makes you feel you have done your best or tried. It's not about making you feel better it is whether the person is still negated and their need goes unmet.

Never come from a defeatist position, your advocating will not be effective. Advocacy is only worth doing if your intention is to be effective and that comes from clarity, truth and a belief in right and justice.

Stay grounded in what you know to be true, so that you are not taken in, especially by someone speaking with authority.

You need discernment to know who to trust, if anyone. The person you are representing is open to great harm, if you get it wrong!

If you going to be an advocate for ME it is about breaking new ground and never accepting "No".